STUDY PROTOCOL

Australian Paediatric Surveillance Unit

Extrahepatic Biliary Atresia

COMMENCING May 1993

OBJECTIVES

To describe the epidemiology of extrahepatic biliary atresia in Australia; to monitor trends in incidence and prevalence; and to evaluate current management and potential requirement for liver transplantation.

INVESTIGATOR CONTACT DETAILS (*Principal Investigator)

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SUMMARY PROTOCOL

Extrahepatic biliary atresia is the most common cause of liver failure and death due to liver disease in childhood in Australia, Europe, North America and Japan. Mortality and morbidity is dramatically reduced by early diagnosis and surgical hepatic portoenterostomy. In Australia, national prevalence and incidence data is not available. The primary objective of this study is to collect basic clinical and epidemiological data to enable national description of the condition.

Continuation of the surveillance is anticipated for 3 years to monitor long term trends and allow collection of sufficient numbers for meaningful epidemiological analysis.

CASE DEFINITION

Any infant born after January 1st, 1985 with:

> *Surgically defined and microscopically confirmed atresia or fibrous occlusion of all or part of the extrahepatic biliary tree.*

REPORTING INSTRUCTIONS

Please report any:

> **new** patients born in Australia with EHBA who have come under your care in the past month.
> any children with EHBA born after January 1st, 1985 who you have seen in the past month and who you have not already reported.

FOLLOW-UP OF POSITIVE RETURNS

A questionnaire requesting further details will be forwarded to respondents who report a case.